



<http://www.strokenetwork.org/>

April 2003

Welcome the April issue of StrokeNet. We hope that you have preserved this winter and are ready for some warm weather. To our readers in the southern hemisphere, enjoy the fall season.

This month Steve writes about changes to the website. David Ray reports on the first meeting of his stroke club in 2003. Kate Adamson's book "Kate's Journey - Triumph Over Adversity" is reviewed. Rhonda Peterson shares some humor concerning the end of winter and losing weight. Then you will find a list of a few of the events that are being held to benefit stroke. Be sure to check out this list and to contact organizations locally to see what is available. Next you will find a review of Stanford University's Stroke Center website. This month's bios are of Pat Provost and Mike Coane. Pat is Human Resources Director for the Stroke Network.

Happy reading.

Lin Wisman, Editor

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Organization Highlights

By Steve Mallory

Things did not go quite as planned last month when the new registration system came on line. The biggest problem was that many members missed our email with an activation link. I have added a web page that explains the activation process, which is essential that the person who registered only perform it. The new page has helped solve that problem tremendously and is no longer a big issue like last month. Thank you for being patient while this problem existed.

The message board was another problem because it was not available for use. It is now available and has been enhanced by deleting the requirement to register with the board in addition to registering with the organization. I have also added another type of dropdown menu that provides links to other resources on our site. One remaining issue is that the message board users are not reading the FAQ.

This is where the answers are for using the message board. I encourage people to read it!

The mailing list has also been enhanced with its own dropdown menu. The menu has links to most of our site resources, especially those important to stroke caregivers. Another enhancement is that I have added the web page section where mailing list members can access their own list preferences. This page is very important and should be explored extensively. It is also a good resource for past caregiver discussions. The message archive and search function for the list is excellent!

The month of March has been one of tremendous change for our web site. My intention is to make the organization more of an actual membership. The various support groups require organization registration in order to use them while the information resources are all open to the visitors. I have found that most people come here just for our resources so I have hopefully made that area easier to navigate with the addition of the new dropdown menus. I wanted to let everyone see exactly what we have and where to go for support or information. I also have everything you ever want to know about the organization at <http://www.strokenetwork.net>. You can get to the site from the About Us dropdown menu. The site also has a menu for questions that you might have. The questions are already formulated and you just make your selection from the Questions menu.

The bottom line is that most of your questions will be answered if you take the time to get to know our site. I have tried to anticipate most of the issues that our existing and future members might have and have already provided a lot of the solutions. If you have a problem or a question please do not hesitate to email me. Lots of problems are peculiar to your particular computer or Internet connection but I understand the majority of the time what you might want to try and will do my best to help. Again, sorry for any inconvenience and thanks for your patience!



Life in New Zealand with a Stroke

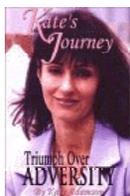
by David G. Ray

March in the part of New Zealand where we live has been the sunniest spell of weather since records were kept. As nice it may have been for us, New Zealand farmers are experiencing difficult times with, for example, a lack of preparation of winter feed. But members of our Stroke Club did not complain at the first gathering of the month. The club had a picnic in a local park pleasantly surrounded by shade trees. Various activities were available for all, however disabled, to enjoy. Some played bowls and even those confined to a wheelchair were able to play and have fun. I elected to play boules or petanque. We quickly formed a number of teams of two each. My wife and I formed one team and although we had never played before, we won the competition.

Petanque is an easy game to play even for those of us who have a disability. You don't need carefully cut lawns as it can be played on any surface. It is an ideal game for stroke victims. We did not earn any prizes except that of the enjoyment of being able to exercise while having fun and comradeship.

At the next meeting of our Stroke Club we are to be addressed by a researcher from Victoria University on Aphasia following stroke. Very few of our members suffer from Aphasia although a few do experience difficulty in speaking. I well remember that immediately after suffering from my stroke. I had extreme difficulty in speaking and when I could, making coherent sentences. I still have difficulty with words when I am put under any form of stress. This session will be of benefit to our members who no doubt will have plenty of questions, and to the researcher who will be able to further her knowledge of stroke difficulties.

I have reported a year or so ago about my next-door neighbor who was unable to speak after suffering from a severe stroke. With perseverance and a strong will he eventually regained his speech and continues to run his own international engineering business. He has overcome his initial setback and with the same commitment and faith in our own ability, perhaps we too can overcome most of our problems.



Book Review: Kate's Journey – Triumph Over Adversity

By Lin Wisman

Kate Adamson documents her stroke in her book "Kate's Journey - Triumph over

Adversity." The stroke occurred in 1995 when she was 33. Originally from New Zealand, Kate left her native homeland at 19. Much of her life since then has been in California, USA.

At the time of her stroke she was a healthy young woman with two small daughters. She had a brain stem hemorrhage. During the hemorrhage, she was aware of what was happening, but, she was unable to communicate. For some time following the stroke, she could only communicate by blinking.

Her story tells of how one doctor and her husband, a lawyer, fought the common wisdom that she was going to die, and later that recovery would be limited. Unfortunately we live in an age where money talks. It is sometimes easy to make a care decision that is the less expensive rather than the one, which offers the best chance to support recovery. Kate, her family and friends fought for her being admitted to rehabilitation rather than a nursing facility. Most of the medical establishment did not believe she was a good candidate for rehabilitation.

Once she began rehabilitation, the going was not easy. She recounts the journey. While in rehabilitation, she took her first steps, and began the process of learning to talk again. Learning to talk again was her priority. She recounts how she was enabled by a speech pathologist with a positive attitude. Kate also explains the process many stroke survivors go through being tested to see if they can swallow correctly, that is not aspirate liquid into lungs.

Kate does a great job of explaining the slow process and hard work of rehab. She willingly shares her own frustrations, but remarks on her clear decision not to give in to her stroke. She was able to maintain her sense of humor.

She tells of several episodes including being quarantined because of an infection in her feeding tube, attending group cooking therapy, and making home visits during her stay in rehabilitation

She explains the helplessness she felt upon returning home at having to depend on other people. She found she had to adjust from being the one who took care of everything. She had to come to terms with many things and gained a new perspective.

Kate set up stroke group and worked with the Stroke Association. She found herself a national volunteer spokesperson for American Heart Association. This included testifying before the US Congress - for more funds for stroke and heart research

She concludes the book by offering hope and encouragement to stroke survivors. She gives helpful hints on managing medical matters. Both caregivers and stroke survivors will find this section of interest. She explains some of the common experiences of stroke survivors. Finally the book contains a list of exercises, which Kate has found helpful in her recovery.

This is an inspirational story. It will provide motivation to all members of the stroke family.



Fighting the Battle of the Bulge

By Rhonda Peterson

It's spring! It's time to pack away the woolens and don lighter fabric clothing. So I pulled out jeans and tee shirts and found out that my jeans won't zip even while lying prone across the bed! The tee shirts stretch across my body giving new meaning to the words "breathable cotton" and fit only the midriff of my out-of-shape body. It's time for a new wardrobe AND a critical look into a full length mirror resulting in a new goal-to lose weight.

I'm not one to join a health club and pay for the privilege of seeing all the beautiful people who weigh all of one hundred and ten pounds soaking wet exercise their already fit little bodies. I'm embarrassed to change clothes in the women's locker room where the little white towels don't even cover my thighs. But I know the battle of the bulge is fought on the ground of exercise, eating right, drinking plenty of water, and finding the magic solution of putting enough calories in for one's metabolism. But lately my metabolism has been equal to that of a sea slug so I've got to increase the burning of fat within my body thus increasing my metabolism too. Okay, so I've got the theory down. Now for the plan of attack!

My goal is to lose at least twenty pounds. I would look better if I lost thirty pounds but let's be realistic. The first thing I did is to get one of those big forty-eight ounce jugs of water and carry it with me every place I go, drinking at least two full plastic bottles per day. Of course with this new routine I can't roam too far from the nearest ladies room but at least I know my kidneys are in good shape! Besides, my skin is beginning to take on a better appearance from hydrating it from the inside out. The second plan of attack called for exercise. What can I do over the long run that would get me into shape and become a part of my daily life? Sit ups? If I hook my feet under the couch I'll flip the couch on top of me before I get my body into a sitting position! Jumping

rope? I'm a stroke survivor not a gymnast! Exercise videos? For me, exercise and videos don't even belong in the same sentence. Videos mean popcorn with melted butter and exercise is something people do to stay in shape. I can walk. Preferably outdoors would be a good plan. I can start out walking one mile, six city blocks out and six city blocks back. I can eat fresh vegetables and fruit and stay away from fast foods and restaurants. I might even save money for a new wardrobe this way!

The first day went well. I walked at a speed that set my heart pumping and I breathed in through my nostrils and out through my mouth. I slowed down when I needed to rest because I knew I would gain nothing by having a massive heart attack. I had to hurry on the return trip because of walking so far away from the bathroom after drinking eight glasses of water. The first week I lost four pounds. At least it's a start!

I decided to purchase a bathroom scale and weigh myself once a week, any more than that would have a tendency to be compulsive and complicate the end result-that of changing a lifestyle pattern. I'm not starving myself and grab an apple instead of potato chips for a snack. I'm not supplementing with diet pills that, for me, may be a sure fire catalyst to having another stroke. I have to lose weight the old fashioned way; exercise that is manageable, drinking plenty of water, and eating low-fat meals. This is the only way I will win the battle of the bulge.

Right now the muscles in my legs ache from my new routine but if I quit the muscles will turn to flab again. The muscles are resisting exercise and are telling me so by releasing lactic acid which causes muscle aches. But my brain is telling me to continue to get my body in shape. My brain, even one affected by stroke, is telling me that this therapy is good.



Stroke Events 2003

Spring is fast approaching in the northern hemisphere. This is the time when many events are held to aid stroke. Listed below are a few of the events scheduled for the next few months. There are many events, which are not mentioned here. Be sure to check with your local stroke association, hospitals and clubs to see what is happening in your area. The events are often designed with stroke survivors in mind. Before you say, "That's not for me. I'm disabled," check out the possibilities for both stroke survivors and caregivers.

If you live in the US, you or a loved one may wish to participate in a marathon for stroke. The American Stroke Association is offering a program to train people for three marathons. The program provides experienced coaches who will help participants ready themselves for the run and to reach physical fitness milestones. For more information, see their website at

<http://www.strokeassociation.org/presenter.jhtml?identifiant=1005>

If live in the UK be sure to check out the Life After Stroke Awards presented by The Stroke Association. Nominations for the award are due by March 21. See their website at

<http://www.stroke.org.uk/noticeboard/lasa.htm>.

If you live in Toronto, you may want to join the Becel Ride for Heart on Sunday June 1, 2003. See their website at

<http://ww2.heartandstroke.ca/Page.asp?PageID=109&RecordID=365&Src=heart&Language=English&CategoryID=20>.

If you live in British Columbia, check out The Times Colonist 10K, which is one of the largest 10K events in Canada and the second largest in British Columbia. See their website:

<http://ww2.heartandstroke.ca/Page.asp?PageID=109&RecordID=63&Src=heart&Language=English&CategoryID=15>.

If you live in other locations in Canada, check <http://ww2.heartandstroke.ca/Page.asp?PageID=104&CategoryID=4&Src=events> to locate events in your province.

If you live in Northern Ireland, the Northern Ireland Chest Heart and Stroke Association is sponsoring the Glens of Antrim Walking Festival 2003 Friday 11th April - Sunday 13th April, 2003. See their website at <http://www.nichsa.com/html/events/event.php?eventID=51> for more information.

This is a great time to participate in an event.



Website Review

The website of Stanford University Stroke Center, <http://www.stanford.edu/group/neurology/stroke>, provides several types of information. These include medical therapies, advanced surgical techniques, and information on their Research Center.

If you are looking for a good explanation of the different types of stroke click on latest medical

breakthroughs on their home page. In addition to information on the various types of stroke there is a list of warning signs and data on reducing risk. Also included are details on diagnosis, treatment and rehabilitation. There is also data on advanced surgical techniques and drugs.

The Research Center area has several items of interest. These include data on clinical trials, and TPA treatment criteria. Also included is an explanation of Stroke Scales.

This site is a good place to go for general stroke information. If you are a California resident, it is a way to discover stroke services available at Stanford.



Biography: Pat Provost

It has been nearly six years since my stroke. It fades to a blurry memory. I can barely remember what it felt like to be fully able. I remember the stressful life I led. Always running to and from the office where I worked at a job that I was not always passionate about. I know now that returning to work after my stroke was a very unrealistic goal. I learned that all strokes are not alike. One stroke survivor cannot compare their recovery with that of another. To evaluate our progress based on the progress of another is completely unfair and unrealistic. My stroke occurred on Good Friday in 1997. I was 42 years old and trying to live my life all at once -- working full days and taking university courses at night. I also wanted to balance my life by getting more exercise. I wanted to have fun too. I chose a sport that I had great passion for when I was younger: equestrian riding. I am grateful to have done this when I had the ability.

Like many of my friends who are stroke survivors, I was very surprised to have a stroke at such a young age. I had no apparent risk factors although my father had heart disease and died of cardiac arrest in 1995. I never smoked and had good blood pressure and cholesterol levels. I was not obese and I had no signs of diabetes. I was very health conscious and strove to live a healthy lifestyle as much as possible during the 1990's rat race.

Easter arrived early in 1997. Good Friday fell on March 28th. Mom was still in Florida. My husband Carl worked that day so I decided to take my Sunday riding lesson on Friday in order to be free for Easter celebrating. Spring was in the air. The snow had nearly melted and I felt like going jogging just before I left for my lesson. It seemed a good idea to warm up with a good brisk walk and jog around my neighborhood. I took a taxi to the stables just outside of town.

I was given a different horse than usual. He was not happy about being tacked up for a lesson. He did everything he could to prevent me from getting his bridle on his head. I think this horse had psychic abilities because he was not behaving as I had expected. About thirty minutes into the lesson I had a strange sensation, a sound in my head like a drill. My vision dimmed, my left side weakened and then when the horse bucked I fell off. I remember hearing the paramedics looking me over and my friends trying to revive me but I knew something was not good when they found I was paralyzed on one side. Right away they took me in the ambulance to hospital where I was asked all the standard questions to assist in the diagnosis. I had given the correct responses but they confirmed that it was over three hours since my stroke occurred.

I was told I was comatose, but I was very aware of family and friends trying to comfort me but the details are no longer clear. These memories are interrupted by images of a light in my eyes and nurses asking me to not bite the ventilator tube. I was highly medicated and unable to communicate well so I resorted to trying to write messages on my sister's hand. My right side worked fine but I only wanted to sleep. In fact, when I got a phone in my room often I would drift off to sleep during a conversation and leave the receiver off the hook.

I missed my husband terribly and was compelled to call him at all hours of the night just to talk. The medication was probably the cause of my silliness and I would frequently make the nursing staff laugh at my comments. I must have been in denial about my condition because I was very concerned about calling my employer to report my absence from work. An orderly informed me that my office would be closed on Easter Monday so I had nothing to worry about. I was still living with the same agenda as before my stroke. I wanted to call my riding teacher to cancel my lesson the next weekend in case I was not able to ride yet.

I seemed to be joking about everything until my doctor brought me back to reality. He asked me if I knew what happened and I said that I understood that I had a little stroke. This seemed to annoy him and he told me that it was NOT a little stroke. It was a Big Stroke and that I had a long road ahead of me and that I needed to begin physical therapy as soon as possible even if it meant doing it in my bed. This guy was really gentle in the ER but with this he made things very clear for my immediate future. Soon I would meet my physical therapist, Josee, who met me in the PT room and helped me from my wheelchair to the exercise bed. I needed to learn how to pivot and transfer from my bed to a chair. After a few sessions I began to trust my weak leg to

support me. I could actually put my full weight on the left side without collapsing. Along with PT I needed occupational therapy to learn how to cope with daily living activities. Up until then a nurse had been spoon-feeding me my meals because it was difficult for me to direct a spoon or fork into my mouth without losing the contents.

Before my stroke I showered everyday. After the third day I was told that a family member could assist me to have a bath. I was transported in a canvas hammock Free Willy style. My husband agreed to give me a hand with the bath. I didn't know that this would be my last bath sitting in a tub for a long time.

My occupational therapist, Nathalie, gave me a session to learn how to use a wheelchair. OT was less motivating and harder on my ego than PT. I felt that I was not performing well. I had poor control of the wheelchair and it embarrassed me. I also had some neuropsychological work to do. I had a significant left side neglect, which caused me to ignore my left side. People noticed that I would write only on the right half of a page of paper; I would also eat only from the right side of my plate.

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In summer I love to garden. There are ways to make gardening possible for people with limited mobility so I have embraced container gardening. With the help of my brother-in-law we added a large deck to the back of our home. It allows me to spend time outdoors in the summer. I have also learned how to cook again. So has my husband. This is where pacing, planning and prioritizing come in to play.

Basically, life after stroke is creating a lifestyle that is possible and realistic for the way one's abilities and interests drive them. I miss the spontaneity I used to enjoy but most things I miss can be realized with planning. We must never give up. I chose to take joy.

I have come to believe that in order to be happy one has to live one's best life. To me this means no longer expecting perfection but instead living on my own terms and squeezing as much living into whatever part of my body is working. I have to remember that my stroke was a personal tragedy but also that it could have been much worse. I did not lose everything. Had I not suffered the stroke I would never have known how much I am loved. I have made many good friends from Internet stroke support. My work at the Stroke Network has made me feel appreciated and worthy of the respect that I need.

I never give up hope of a full recovery but I have learned how to live with my disabilities. I am able to live with what I have in this moment. It can only get better.

Read the biography in its entirety at <http://www.strokenetwork.org/newsletter/bios/pprovoost.htm>

Biography: Mike Coane

On the sixth anniversary of his stroke Mike writes... In December 1996, while sitting at my desk at home in Germany at about 8:20PM and smoking what proved to be my last cigarette, my left hand went numb. I had no idea what was happening to me since I knew less than nothing about stroke. I then realized my dog hadn't been fed, so I went downstairs to the kitchen falling down the last third of the spiral staircase when my left leg went numb. I couldn't reach our doctor, so I called my neighbors, and they came over and called an ambulance, which took me to the local hospital.

Since the local hospital didn't have a neurology department, a staff internist ordered the first of several CTs. It was determined that I had had a stroke. The next day I was transferred to the stroke clinic of a hospital about 20 miles away, where I was attached to a machine, which would slowly drip heparin into my arm for the next several weeks. I started PT almost immediately.

The neighbors called mutual friends and explained what had happened, and that my wife was on a business trip to Nuremberg. The friends started calling hotels in Nuremberg until they found my wife who then hurried to the hospital. She also called my parents who were wintering in their Florida home. They flew home to Chicago to get some winter clothes and then flew to Germany to see me. My daughters, who were in Milan at the time, also came.

Then after about five weeks in the hospital during which I had the pleasure of some very uncomfortable tests including several more CTs, an echocardiogram, an angiogram and an MRI, it was determined that I was ready to go to rehab. Application was made at one of the best rehabs in Germany at which I was accepted. In anticipation of this move, I was weaned from the heparin machine and given an oral anticoagulant named Marcumar. Coumidin, which is usually used in the US, is not that popular here. Then after a few days, the MRI detected a slight hemorrhage in my parietal lobe -- not uncommon when weaning from heparin to an oral anticoagulant -- so they decided to wait before transferring me to rehab.

Then the day after the Superbowl in 1997, I was transferred to rehab where I spent several hours a day doing physical and occupational therapy. Finally in early April they determined that I was ready to go out into the world. So, I left rehab in mid-April and came home to daily bouts of PT (4x per week, 1x in a pool) and OT (1x per week). This rather massive infusion of therapy has taken me to the point that I have almost full control of my left arm, although the fine motor control of my left hand is less than ideal, and I can walk almost anywhere unaided, although not very elegantly.

I'm now doing PT 4 times a week (no more pool), and despite the allegations of almost everyone in the stroke rehabilitation industry, I still feel that I have some room for improvement. I'm also able to drive a car with automatic transmission. I wouldn't have achieved anywhere near my current status were it not for the support of my wife, doctors, therapists, neighbors and friends.

Read about how Mike got to Germany from Chicago, USA at http://www.strokenetwork.org/newsletter/bios/mcoane_history.htm

The Stroke Network is a registered 501(3)c non-profit organization. We are an on-line stroke support organization and are available to everyone worldwide. Since 1996 we have provided stroke support and information to nearly 10,000 people and to hundreds of thousands of visitors to the site. The Stroke Network is the homepage for a network of several other smaller web sites owned by The Stroke Network Inc

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